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ABSTRACT

The paper describes adult homes and room and board homes serving persons with disabilities in Onondaga County, New York. Visits were made to eight adult homes and five room and board homes. Briefly considered are ownership and licensing regulations, referrals, and admission criteria. Observations at the homes are offered. Concerns are raised about safety, lack of staff training, lack of coordinated screening of applicants, the high number of people living in each facility, location of homes in bad neighborhoods, the lack of privacy, the poverty of persons living in the homes, the inactivity that characterizes life in the homes, the lack of personal hygiene, and the tendency of people in these homes to disappear from the mental health and developmental disability systems. Recommendations include the following: referrals to these homes by agencies should stop; agencies should review each person placed in one of these facilities and develop an alternative placement plan; agencies should develop appropriate alternatives for people who are now referred to these homes; and agencies should investigate a change in the way the State Supplemental Security Income supplement is awarded. (DB)

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Center on Human Policy

THE SERVICE SYSTEM'S HIDDEN PLACES: ADULT HOMES AND ROOM AND BOARD HOMES HOUSING PEOPLE WITH DEVELOPMENTAL DISABILITY AND PSYCHIATRIC LABELS IN ONONDAGA COUNTY

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THE SERVICE SYSTEM'S HIDDEN PLACES:

ADULT HOMES AND ROOM AND BOARD HOMES HOUSING PEOPLE WITH DEVELOPMENTAL DISABILITY AND PSYCHIATRIC LABELS IN ONONDAGA COUNTY

OCTOBER, 1988

by the Center on Human Policy
Julie Racino, Kathy Rothenberg, Bonnie Shoultz,
Steve Taylor, and Rannveig Traustadottir

This report is the final edition of a paper on adult homes and room and board homes in Onondaga County. An earlier, draft version was circulated to members of the Advocacy Board of the Center on Human Policy, representatives of Hutchings Psychiatric Center and Seguin Community Services, the Residential Cluster of the Onondaga County Office of Mental Health, and to a small number of advocacy organizations. The draft version was picked up and reported on by the Syracuse news media, and generated a great deal of public interest in the issues raised in the report.

This final version reflects discussions with a variety of organizations and individuals, many of which took place after the draft version was disseminated. The report is now being disseminated to a wide variety of interested parties.

Introduction

Based initially on a concern raised by a relative of a person with a developmental disability, the Center on Human Policy and its Advocacy Board decided to examine the use of room and board and adult homes for people with developmental disability and psychiatric labels in Onondaga County. Both Seguin Community Services and Hutchings Psychiatric Center refer people to and assist people through the process of moving into these homes.

To begin the examination, Center on Human Policy staff met with representatives from both Hutchings Psychiatric Center and Seguin Community Services to obtain their perspectives on these issues. Advocacy Board members and staff then visited a total of eight adult homes and five room and board homes during May and June of 1988. Visits were made to all homes (except two) identified by officials as the places to which they refer people. The two homes that were not visited were expensive private-pay facilities for elderly people. Attached is a list of the places that were visited and the people who visited them.

The following outlines very briefly some of our observations.

Three Main Categories of Homes

The adult homes and room and board homes fall roughly into three categories:

(1) "Adult homes" that mainly serve elderly people with no specific problems other than that they are elderly. These places, with some exceptions, serve only a few people with developmental disabilities and mental health problems.

(2) "Adult homes" that serve a mixed group of people of various ages who have a wide variety of problems, including developmental disabilities and mental health problems. Some of these facilities are specialized in the sense that they prefer to serve a particular group of people such as people with developmental disabilities or males whose primary problem is alcohol or drug abuse.

(3) "Room and board homes" where a very mixed group of people live, including elderly people and people with disabilities and mental health problems. Room and board homes provide meals and shelter only.

Ownership and Licensing

These homes are all privately owned and run, either for profit, or not-for-profit. The adult homes are licensed and regulated by the Department of Social Services (DSS). The room and board homes are not licensed or regulated in any way; they are not even required to go through fire inspections.

Referrals and Admission Criteria

According to the agency people we talked to, referrals to these two types of homes are very easy compared to referrals to

group homes or other community residences funded through the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities. The community residences and group homes typically have long waiting lists, long screening and preparation periods and negotiations about what services and programming the community residences will provide to meet the person's needs.

There is no screening process or waiting lists for the room and board homes. People just rent a room and move in. Many are discharged by Hutchings or Seguin when they move into a board and room home. There is a large turnover in these homes and often no one knows what becomes of people who move out.

The procedure of getting people into the adult homes is a little more complicated, and some of the adult homes have waiting lists. One of the admission criteria is that people must not need a high level of care. Adult homes provide 24 hour staff presence within the facility and medication administration, but do not have staff to provide much personal care. The agencies stay in contact with some of the people who move to the adult homes.

The Total Population and Size

According to one of the agencies the total population of adult homes in Onondaga County is over 600 people. The same agency also informed us that no one knows the exact number of people living in room and board homes. The number of people could range anywhere from 80 to 150 people. The places we

visited varied greatly in size, ranging from nine to 173 people in one place.

A SHORT DESCRIPTION OF WHAT WE SAW

Based on information provided by agency representatives, approximately 31 Seguin clients live in adult and boarding facilities, while Hutchings has referred over 60 people to these facilities in the past year.

Room and Board Homes

We were escorted by Seguin staff and visited a total of five homes. All were located in low-income neighborhoods where the area was heavily littered with debris and many of the surrounding homes and buildings were in extremely poor condition. The homes we visited were very old structures, housing from nine to 17 residents. Crumbling plaster, crooked floors and stairways, and broken furniture were characteristic of all the homes. In addition to being poorly maintained structurally, the houses were not kept clean. Food, dirt, and other particles littered the rugs, which were usually very worn and ragged. Linoleum was in poor condition as well as being dirty.

Living areas often consisted of dormitory-style tables and chairs arranged in a barren room. It was rare to see comfortable chairs or couches. When upholstered furniture was present, it was soiled and in poor condition.

The kitchens were set up cafeteria-style with long tables and rows of chairs. In most instances, the kitchen was off-limits for residents, except in a couple of places where people were allowed to make a sandwich or snack. However, none of the places allowed residents to cook a complete meal. Meals are served at set times of the day and if a person is not present at the specified meal time, he or she goes without that meal.

Some of the homes had single bedrooms, others had as many as four people in a room. The bedrooms were very small and crowded. Mattresses were often on the floor without linens, walls were usually barren, and there was a lot of clutter on the floors. In some instances there were no curtains or shades on the windows. Bathrooms were shared by a large number of people. Fixtures were old and often towels and toilet paper were missing.

Many of the people living in the boarding homes did not work. In the middle of the afternoon, people were lying around, watching TV, or playing cards. Some sat alone or with others, some were talking or smoking cigarettes.

Some of the people told us that constant fighting among residents was a problem. In one home, the proprietor snapped at one of the residents to "sit up" as we entered the living room where he was reclining on a couch.

Adult Care Homes

We visited eight adult homes. Many of these facilities were in low income neighborhoods. The smallest adult home we saw

had 20 people living there and the largest had 173 people.

Despite the fact that all adult homes are required to have an activities schedule, we saw almost total inactivity. No matter what time of day we visited these homes, people were in bed, sleeping in the middle of the day, sitting around watching TV, smoking or staring at the walls. The people were very passive and many looked depressed or sad. Rarely did we see any interaction between people, either among residents, or between staff and residents.

Many places provided no opportunity for privacy. For example, one of the homes had a big dormitory-style bedroom shared by 20 men. Each man had only a small iron locker for his personal belongings. A few places had a limited number of single bedrooms. More commonly people had to share a room with someone. In one instance the bedroom doors had name plates with the name of companies that donated money to the organization. Bedroom furniture was utilitarian and in most cases all the bedrooms had the same type of beds, dressers, lamps, curtains, etc. Very little in the way the bedrooms were furnished exuded a sense of the individuality of the people living in them.

In all cases but one the residents were forbidden to go into the kitchen. Only in one place did we see food available for the residents. It also seemed to be common that if residents did not make it to scheduled meals (for example, if they had a job or community activity and came home late), they would risk going without a meal.

Upon questioning we found that direct care staff had very

little or no training to work with people who have disabilities or mental health problems. Few staff were working at any given time. Following are some examples of staff-resident ratio. In one place where 20 people live there is one staff person on duty at a time. This staff person also has to prepare food for the 20 people. In another instance there were 2 staff people for 60 elderly residents. (In addition there was an activities director and kitchen staff shared by about 100 other residents.) In the third instance there were 30 residents and 2 direct care staff. (In addition there were other support staff shared by a number of other residents.)

Most of the residents were noticeably badly dressed, some had decayed teeth or teeth missing. Most of the residents do not work and spend much of their lives in in these homes.

Department of Social Services regulations ("Part 487, Standards for Adult Homes") do not mandate intensive services at these facilities and, in fact, require a minimum of activities for people living there. It is unclear whether these facilities comply even with these minimum requirements. In one case the owner said: "We are required to have an activities schedule, but few participate. When New York State comes to inspect I just tell them what they want to hear."

Some of the adult homes made an attempt to create a nice atmosphere, others did not bother, and in some of the homes the walls were noticeably bare, in the bedrooms, halls, stairways, living rooms, etc.

Conclusion

One agency's representative expressed concern about a number of issues regarding both room and board and adult homes. Among the things mentioned were: concern about people's safety; environmental issues; the fact that staff does not have training to work with people who have mental health problems and developmental disabilities; lack of coordination in screening of applicants to these homes; the high number of people living in each facility; and the location of these homes in some of the worst neighborhoods in town. Our observations confirmed that these are issues of concern.

In addition, we would like to emphasize the lack of privacy; the poverty of people living in these homes; the inactivity that characterizes life in these homes and the atmosphere of depression and sadness; lack of personal hygiene; the fact that people can go without food if they don't come to scheduled meal times; and the fact that when people go into these homes they tend to disappear from the mental health and developmental disability "systems" and often no one knows what happens to them.

THE USE OF ROOM & BOARD AND ADULT HOMES FOR PEOPLE WITH DEVELOPMENTAL DISABILITY AND PSYCHIATRIC LABELS IN ONONDAGA COUNTY: ISSUES AND RECOMMENDATIONS

As a result of these visits, and based on current trends in supporting people with developmental disabilities and mental health diagnoses in the community, we have identified the following issues:

ISSUES

1. SIZE: Both the room and board and the adult homes are extremely large, considering emerging standards for the size of community residential programs. They range in size from nine to 16 people for the room and board homes and from 16 to 173 for the adult homes. As such, they are inappropriate places for people with disabilities to live, regardless of the conditions in the homes. Proprietors told us that regulations are "causing" larger and larger adult homes to be established, because it is economically not feasible to operate a small home and make a profit. One proprietor told us of plans by other companies for 200-300 bed adult homes for elderly people in the county.

2. QUALITY: In the room and board homes, which are not regulated by any governmental agency, quality concerns extended

to basic issues such as cleanliness. In the adult homes, people's quality of life was the major issue. In both types of settings, many of the people appear to be inactive during the day (sleeping, sitting around, wandering the halls, etc.) rather than out in the community engaged in meaningful activities such as work. Mealtimes are generally regimented, and access to food at other times is severely restricted, except in one place. Expectations of the people referred to these homes is apparently very low, both on the part of the referring agency and the homes. People are not expected to work, to be a part of the community, to cook or clean up for themselves, or to take responsibility for themselves. The people in the homes are not provided with training or assistance to gain these skills, so they may lose the skills they once had.

3. LACK OF REGULATION/OVERSIGHT OF ROOM AND BOARD HOMES: Because the room and board homes are unregulated and unmonitored, poor conditions are allowed to persist. No public agency accepts responsibility for the quality of life and well-being of people placed there.

4. LACK OF APPROPRIATE ALTERNATIVES TO THESE SETTINGS: In discussions with Seguin and Hutchings officials and staff, we have been told repeatedly that both the room and board and adult facilities are "better than the streets"; in other words, that these facilities meet some needs and, without them, people would be homeless and without regular meals. We also have been told

that some family members and residents of the facilities themselves choose the adult and room and board facilities over the available alternatives (homelessness or institutionalization at Syracuse Developmental Center or Hutchings Psychiatric Center).

We do not find this defense of room and board and adult facilities compelling and believe that to view them in terms of their superiority to homelessness is to miss the point. We--and, we believe, a significant sector of this community--have higher standards for services for people with developmental disabilities and mental health diagnoses and, indeed, for elderly people and those with other needs. If the problem is a lack of alternatives--affordable and decent housing and a range of support services--then the solution is to develop those alternatives, rather than to attempt to justify inappropriate facilities.

5. PEOPLE WITH MANY DIFFERENT NEEDS LIVING TOGETHER: People with very different needs live together in these facilities. We saw elderly people and people with a variety of physical and mental disabilities living together in these homes, often with roommates not of their own choosing. People who had other choices would rarely choose such a situation for themselves or their family members.

6. THE COMPLICITY OF SEGUIN COMMUNITY SERVICES AND HUTCHINGS PSYCHIATRIC CENTER IN PERPETUATING THIS SITUATION: The issues and problems addressed in this report are complex. Many public and private agencies contribute to the continued use of room and board and adult homes for people with developmental disability and psychiatric labels. While recognizing the complexity of this issue, we believe that Seguin Community Services and Hutchings Psychiatric Center must assume some level of responsibility for the placement of people at these facilities and their quality of life. Not only are Seguin and Hutchings local representatives of the state agencies responsible for developmental disabilities (Office of Mental Retardation and Developmental Disabilities) and mental health (Office of Mental Health), respectively, they actively place people at these facilities. Any agency that refers people to these facilities and actively assists in their placement there must assume responsibility for perpetuating their existence.

RECOMMENDATIONS

This section of the report contains recommendations flowing from this report. These are presented as beginning steps to provide constructive alternatives to the use of room and board and adult facilities for people with developmental disability and psychiatric labels.

These recommendations are directed to agencies and people

concerned with the mental health and developmental disability systems. We are not addressing recommendations to the Department of Social Services (DSS) or to room and board and adult facilities. While we would hope that this report will stimulate positive efforts on the part of DSS and the facilities themselves, we do not believe they should be held responsible for the perpetuation of a situation when publicly funded agencies responsible for developmental disabilities and mental health have not demonstrated higher standards for the populations they serve. Finally, we do not address issues related to other people living at room and board and adult facilities, especially elderly people. We hope that this report will encourage organizations concerned with these people to undertake a similar review.

1. REFERRALS TO THESE HOMES BY SEGUIN COMMUNITY SERVICES AND HUTCHINGS PSYCHIATRIC CENTER SHOULD STOP.

Seguin Community Services and Hutchings Psychiatric Center should immediately halt referrals to room and board and adult facilities. As long as Seguin and Hutchings view these facilities as an acceptable option, other alternatives will not be developed.

For each person who otherwise would have been placed at one of these facilities, alternatives, including decent housing with appropriate support services, can and should be developed.

2. SEGUIN COMMUNITY SERVICES AND HUTCHINGS PSYCHIATRIC CENTER SHOULD REVIEW EACH PERSON THEY HAVE PLACED IN ONE OF THESE FACILITIES AND DEVELOP AN ALTERNATIVE PLACEMENT PLAN FOR EACH.

Seguin and Hutchings should undertake a review of each individual they have placed in these facilities in the past and develop a plan to address that individual's housing and service needs in an alternative in the community. It is essential that people themselves and, if appropriate, their families, be involved in the development of these plans and be presented with positive options.

3. SEGUIN COMMUNITY SERVICES AND HUTCHINGS PSYCHIATRIC CENTER, IN CONJUNCTION WITH THE ONONDAGA COUNTY DEPARTMENT OF MENTAL HEALTH, SHOULD CREATE OR OBTAIN APPROPRIATE ALTERNATIVES FOR PEOPLE WITH DEVELOPMENTAL DISABILITY OR PSYCHIATRIC LABELS WHO ARE NOW REFERRED TO THESE HOMES.

Seguin Community Services and Hutchings Psychiatric Center together with the County Department of Mental Health should accept responsibility for creating or obtaining appropriate, supportive alternatives for people with disabilities. These agencies must provide for services in more normal, more attractive, and more competency-enhancing ways and settings. For example, housing subsidies (not just Section 8), meals-on-wheels, homemaker services, scheduled meaningful leisure activities or employment, medication administration and supportive contact/monitoring can be provided or arranged for in a number of ways in people's own homes or apartments. People

can be helped to find roommates or a larger support network to meet their needs for social contact and affiliation. Skills training in a variety of areas (depending on each person's needs and desires) can be provided. Case managers who have low caseloads and are able to develop warm, supportive relationships with people are necessary to assist the person and oversee the services they receive.

4. HUTCHINGS PSYCHIATRIC CENTER AND SEGUIN COMMUNITY SERVICES SHOULD INVESTIGATE A CHANGE IN THE WAY THE STATE SSI SUPPLEMENT IS AWARDED.

As representatives of state agencies responsible for developmental disability and mental health services, respectively, Seguin and Hutchings should address policy and funding issues that restrict the options of the people they serve. While Seguin and Hutchings cannot revise state policies and funding mechanisms, they can bring these matters to the attention of state officials and policy makers.

A major issue limiting people's options is the availability of sufficient income to afford decent places to live. At this time, people on SSI (Supplemental Security Income) who live in group settings are awarded a larger supplement to their SSI checks than people who live on their own or with their families. The SSI payment to people who are not in group settings is frequently not enough to pay the rent in a decent apartment, and cannot cover supportive services the person may need. Accordingly, people are forced into congregate

levels of care to get housing and supportive services. The laws creating the state SSI supplement need to be reviewed and revamped as one of many ways to eliminate disincentives for people to move out of group care and into homes of their own where they can receive the supports they need.

5. THE RESIDENTIAL CLUSTER OF THE ONONDAGA COUNTY DEPARTMENT OF MENTAL HEALTH SHOULD PLAY AN ACTIVE ROLE IN SERVICE PLANNING AND DEVELOPMENT FOR PEOPLE REFERRED TO THESE HOMES.

One of the ironies of this report is that community developmental disability and mental health services are subjected to greater scrutiny and oversight in Onondaga County than in any other county in New York State. Among other groups, the Residential Cluster, an advisory committee to the Onondaga County Department of Mental Health, has played an active role in the review and monitoring of community residential services in developmental disabilities and mental health. Yet room and board and adult facilities are "hidden places" whose residents are "invisible" to groups like the Residential Cluster concerned with developmental disabilities and mental health. It is time to make this population visible and to take into account their needs in planning for services in this community.

The people referred to these room and board and adult facilities are, in many ways, a "hidden population" of people. While it is expected that people with disabilities who are involved in the services funded through OMRDD and OMH will reside in small homes, be engaged in meaningful activities, be

learning skills, and so on, nothing of the kind is expected on behalf of these individuals, who are in many ways invisible. The Cluster is one mechanism set up in this county to "make visible" people with disabilities and the services they receive and the services that must be adapted or created to support people with disabilities to lead quality lives in the community.

6. A BROAD COMMUNITY COALITION SUCH AS THE COALITION FOR HEALTH AND WELFARE SHOULD TAKE A STAND ON THESE ISSUES.

A broad community coalition should examine the issues raised by the presence of these homes. The homes exist because people are in poverty and cannot afford decent housing and services, because people are seen as appropriate for custodial care, because people are viewed as unable or unwilling to cook, clean, and medicate themselves, and because these homes are seen as better than the alternatives (usually the street or an SRO hotel). There are no positive reasons for their existence. A broad community coalition needs to look at ways of resolving the problems that force people into these homes and to tackle the policy issues on both the local and state levels.

List of places that were visited:

Adult Homes:

Kalet's Home for Adults, 504 Delaware St.

Loretto Adult Home, 750 East Brighton Ave.

Highland Home, 212 Highland St.

New Hope Home, 120 Gifford St.

East Side Manor Home for Adults, 7164 E. Genesee, Fayetteville

Lincoln-Elms, 168 Lincoln Ave.

Stafford Manor Home for Adults, 121 Kellogg

Evergreen Manor Home, 4181 Barker Hill Rd., Jamesville

Room and Board Homes:

Seaborgs, West Onondaga St.

Seaborgs, East Genesee St.

Krichbaums, 706 Tully St.

Halsteads, 311 Shonnard St.

Renaissance House, West Onondaga St.

Visited by:

Kathy Hayduke, Julie Racino, Kathy Rothenberg, Bonnie Shoultz, Steve Taylor, Rannveig Traustadottir, Susan Young.